

ORIGINAL

49 / "Downs"

ADDRESS

By

C. EVERETT KOOP, M.D.

SURGEON GENERAL

U.S. PUBLIC HEALTH SERVICE

AND

DEPUTY ASSISTANT SECRETARY FOR HEALTH

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES



PRESENTED TO THE NATIONAL DOWN'S SYNDROME CONGRESS

SAN ANTONIO, TEXAS

OCTOBER 27, 1984

(GREETINGS TO HOSTS, GUESTS, FRIENDS, ETC.)

I'M PLEASED TO BE HERE THIS MORNING TO TAKE PART IN THE NATIONAL DOWN'S SYNDROME CONGRESS AND CONTRIBUTE WHAT I CAN TO THESE PROCEEDINGS. AND IT IS A SPECIAL PLEASURE TO SHARE THIS PLATFORM WITH THE ASSISTANT SECRETARY OF EDUCATION, THE HONORABLE MADELEINE WILL.

I WILL SOON COMPLETE THE THIRD OF MY FOUR-YEAR TERM IN WASHINGTON AS SURGEON GENERAL. IN THAT TIME I HAVE GATHERED CERTAIN IMPRESSIONS ABOUT OUR CAPITAL CITY THAT WILL STAY WITH ME THE REST OF MY LIFE. AND AMONG THEM ARE THE NAMES AND FACES OF THE FEW PEOPLE IN WASHINGTON WHO ARE NOT LAWYERS, ACCOUNTANTS, PROGRAM ANALYSTS, POLICY CONSULTANTS, LOBBYISTS, OR CONTRACTORS.

I THINK I'LL ALWAYS REMEMBER THE FEW PEOPLE WHO RISE ABOVE SUCH A CROWD...WHO ARE IN WASHINGTON NOT FOR THE PERSONAL MONETARY GAIN THAT'S AVAILABLE BUT FOR THE OPPORTUNITY THAT'S AVAILABLE FOR HELPING THOSE OF OUR CITIZENS WHO NEED IT MOST: THE ELDERLY, THE DISADVANTAGED, THE POOR, THE HANDICAPPED, AND CHILDREN.

AMONG THOSE FEW -- AND IN THE VERY FRONT RANK -- WOULD BE MY FRIEND AND COLLEAGUE, ASSISTANT SECRETARY WILL. I KNOW A LITTLE BIT ABOUT THE JOB SHE HAS TO DO...AND THE JOB SHE HAS DONE. AND I URGE YOU ALL TO GIVE HER ALL THE ENCOURAGEMENT AND SUPPORT THAT YOU CAN.

MRS. WILL EXERCISES STRONG PERSONAL AND MORAL FORCE IN BEHALF OF FEDERAL PROGRAMS DESIGNED TO HELP DISABLED, DISADVANTAGED, AND DEFENSELESS PEOPLE...YOUNG PEOPLE AND CHILDREN IN PARTICULAR...WHO CANNOT ALWAYS HELP THEMSELVES. HERS IS A BIG JOB, BUT NOW AND THEN IT FALLS IN DANGER OF BEING OVERWHELMED BY SOME OF THE LESS ATTRACTIVE ELEMENTS IN THE WASHINGTON ENVIRONMENT. THAT'S WHEN MRS. WILL AND A FEW OTHERS OTHERS LIKE HER NEED THE SUPPORT OF GOOD PEOPLE FROM AROUND THE COUNTRY, PEOPLE SUCH AS YOU HERE TODAY.

ALTHOUGH WE ARE OFTEN ON THE SAME SIDE IN THE SAME BATTLES, ASSISTANT SECRETARY WILL AND I DON'T OFTEN SHARE THE SAME PUBLIC PLATFORM, AS THIS MORNING. THEREFORE, I HOPE WITH YOUR INDULGENCE, I HAVE SEIZED THIS OPPORTUNITY TO SHOW MY DEEP REGARD FOR WHO SHE IS AND WHAT SHE DOES.

HAVING SAID THAT, I MUST ALSO CONFESS THAT I WAS MIGHTILY TORN OVER YOUR KIND INVITATION. IT PRESENTED A CONFLICT WITH ANOTHER EVENT OF SOME CONSEQUENCE, EVEN THOUGH IT'S A VERY LOCAL AND PRIVATE EVENT.

RIGHT NOW, AS I AM ADDRESSING YOU, A YOUNG MAN NAMED JOSHUA ANDREW ROSENBLUM IS CELEBRATING HIS BAR MITZVAH IN EVANSTON, ILLINOIS. HIS FATHER, VICTOR ROSENBLUM, IS A WIDELY RESPECTED PROFESSOR OF CONSTITUTIONAL LAW AT NORTHWESTERN UNIVERSITY. AND I MUST SAY I WAS GREATLY TEMPTED TO JOIN VICTOR AND LOUIS AND THEIR 12 OTHER CHILDREN IN THE PEWS OF THE BETH EMET SYNAGOGUE THIS MORNING TO CELEBRATE THE "COMING OF AGE" OF THEIR 13TH CHILD, JOSHUA.

JOSHUA, AS YOU MIGHT HAVE GUESSED, IS A DOWN'S SYNDROME CHILD. THAT IS NOT AN INCIDENTAL BIT OF INFORMATION, OF COURSE. IT'S IMPORTANT...BUT IT'S NOT THE KEY PIECE OF INFORMATION ABOUT HIM AND HIS FAMILY. THE REALLY IMPORTANT THING TO KNOW ABOUT JOSHUA IS THAT HE AND HIS EXTRAORDINARY FAMILY SHARE STRONG BONDS OF LOVE, OF TRUE CLOSENESS, OF MUTUAL SUPPORT -- YES, HE SUPPORTS THEM AS THEY HAVE SUPPORTED HIM -- AND THEY SHARE STRONG TIES OF RELIGION AND CULTURE.

TODAY, JOSHUA, WHO MIGHT BE CONSIDERED A "HANDICAPPED" CHILD, WILL TAKE HIS RIGHTFUL PLACE -- A PLACE HE HAS EARNED, ACCORDING TO TRADITIONAL TESTS -- IN A JEWISH LINE OF HISTORY THAT REACHES BACK NEARLY 6,000 YEARS. AND HE WILL TAKE PART IN THE RELIGIOUS SERVICE IN A SANCTUARY FILLED WITH HIS PARENTS AND SIBLINGS AND FRIENDS.

AND I HAVE TO ASK, "HOW MANY PEOPLE IN OUR SOCIETY...WHOM WE SAY WERE BORN NORMAL...HOW MANY OF THEM ARE TRULY HANDICAPPED BY THE ABSENCE OF LOVE AND A SENSE OF 'PLACE,' TWO THINGS THAT JOSHUA HAS IN ABUNDANCE." THE ANSWER, I AM SAD TO SAY, IS PROBABLY "HUNDREDS OF THOUSANDS."

AND, TO ME, THAT IS THE HEART OF WHY WE'RE HERE TODAY. WE KNOW THAT CHILDREN WITH DOWN'S SYNDROME ARE GOING TO HAVE A MORE DIFFICULT TIME IN LIFE AND MAY NOT ABSORB AS MUCH FROM THE EXPERIENCE AS THE REST OF US. BUT WE ALSO KNOW THAT THEY HAVE A RIGHT TO EVERY BIT OF LIFE THEY CAN ABSORB.

AND WE ALSO KNOW THAT THE QUALITY OF THEIR LIVES MAY BE EVERY BIT AS SWEET AND RICH AS THE LIVES OF THEIR MORE NORMAL SIBLINGS AND FRIENDS. JOSHUA ROSENBLUM AND MANY THOUSANDS OF OTHER DOWN'S SYNDROME CHILDREN HAVE TAUGHT US THAT. IT IS IN OUR POWER TO HELP EACH OF THESE CHILDREN ACHIEVE THAT KIND OF LIFE...AND WE ARE HERE TODAY AS TESTIMONY OF OUR PROMISE THAT WE WILL DO JUST THAT.

AS YOU CAN PROBABLY DETECT, I DON'T COME TO THIS SUBJECT OF DISABLED OR HANDICAPPED CHILDREN WITH ANY DETACHMENT. AS YOU KNOW, I SPENT MY ENTIRE PROFESSIONAL LIFE AS A PEDIATRIC SURGEON SERVING THE NEEDS OF SUCH CHILDREN AND THEIR FAMILIES. HENCE, IT HAS BEEN DIFFICULT FOR ME OVER THE PAST 30 MONTHS TO MAINTAIN A CERTAIN CLINICAL DETACHMENT WHILE WRESTLING WITH THE ISSUES WRAPPED UP IN THE SHORT, TRAGIC HISTORY OF THE CHILD KNOWN AS "BABY DOE."

HOWEVER, FOR THE NEXT SEVERAL MINUTES I'M GOING TO TRY TO CONVEY WHAT SOME OF US IN GOVERNMENT HAVE BEEN WORRYING ABOUT, EVER SINCE THAT DAY IN APRIL 1982, WHEN "BABY DOE" DIED.

I AM CAREFUL TO SAY "SOME OF US IN THE GOVERNMENT" BECAUSE -- EVEN TODAY, AFTER MOST OF THE DUST HAS SETTLED -- THERE IS NO COMPLETE AGREEMENT AS TO WHAT REALLY HAPPENED, WHAT IT ALL MEANS, AND WHAT WE HAVE TO DO NEXT. AND IN THIS RESPECT, I'M AFRAID THE GOVERNMENT ACCURATELY REFLECTS THE PROBLEM THAT IS ABROAD IN THE LAND GENERALLY.

YOU WILL RECALL THAT "BABY DOE," OR "THE BLOOMINGTON BABY," AS THE LITTLE BOY WAS FIRST KNOWN, WAS BORN IN BLOOMINGTON HOSPITAL, INDIANA, ON APRIL 8, 1982. HE REPORTEDLY HAD MULTIPLE CONGENITAL DEFECTS, INCLUDING AN ESOPHAGEAL OBSTRUCTION AND DOWN'S SYNDROME. AN ATTENDING SURGEON SAID THE OPERATIVE MORTALITY FOR CLEARING UP THE OBSTRUCTION WAS ABOUT 50 PERCENT. AN ATTENDING PHYSICIAN SAID THE INFANT WOULD GROW UP SEVERELY RETARDED.

ON THE BASIS OF THIS INFORMATION, THE PARENTS OF "BABY DOE" DECIDED THAT NO FURTHER MEDICAL ASSISTANCE OR NOURISHMENT BE GIVEN TO THEIR CHILD.

BUT MEDICAL OPINION AT THE HOSPITAL WAS DIVIDED. IT'S IMPORTANT TO REMEMBER THAT FACT, BECAUSE IT HAS BEEN ARGUED THAT THE POSITION TAKEN BY THE GOVERNMENT AND BY SOME CIVIL RIGHTS ADVOCATES IN THIS CASE HAS BEEN A POSITION AGAINST THE JUDGMENT OF PHYSICIANS. BUT THERE WAS NO SINGLE MEDICAL POSITION. FROM EVERYTHING WE NOW KNOW, HAD THERE BEEN A FORUM OF SOME KIND FOR DISCUSSION AMONG THE HOSPITAL'S PHYSICIANS, A MAJORITY MIGHT WELL HAVE OPPOSED THE PARENTS' DECISION.

FROM THE VERY BEGINNING, THE "BABY DOE" CASE HAD 2 SIDES TO ALMOST EVERY QUESTION THAT WAS RAISED...

2 SIDES AS TO WHAT THE TREATMENT OUGHT TO BE...

2 SIDES AS TO WHO MAKES SUCH DECISIONS...

2 SIDES AS TO HOW SUCH DECISIONS ARE MADE...

AND 2 SIDES IN REFERENCE TO WHICH PROCEDURES SHOULD BE FOLLOWED
WHEN THERE IS NO CONSENSUS.

SOME OF THE PHYSICIANS AT BLOOMINGTON HOSPITAL, WHO DISAGREED WITH THE NEGATIVE OPINION OF THEIR COLLEAGUES AND THE DECISION OF THE PARENTS, WENT INTO COURT TO SEEK AN INJUNCTION PREVENTING THE PARENTS' DECISION FROM BEING CARRIED OUT AND, INSTEAD, REQUIRING THAT "BABY DOE" BE GIVEN SOME NOURISHMENT AND SOME MEDICAL CARE. THEIR AUTHORITY WAS THE INDIANA LAW ON CHILD ABUSE AND NEGLECT.

JUDGE JOHN BAKER, A CIRCUIT JUDGE SERVING MONROE COUNTY, HEARD TESTIMONY FROM BOTH SIDES -- EVEN HELD A LONG HEARING IN THE HOSPITAL ITSELF -- AND THEN RULED THAT NO INJUNCTION WAS NECESSARY. IN EFFECT, THE PARENTS WON THAT DECISION.

A SECOND CASE WAS BEGUN WHEN THE COUNTY PROSECUTOR'S OFFICE ENTERED WHAT IS KNOWN IN INDIANA AS A "CHINS" PETITION, THAT IS, A PETITION FOR A "CHILD IN NEED OF SERVICE." SUCH A PETITION IS USED ON BEHALF OF CHILDREN ALLEGED TO BE THE VICTIMS OF ABUSE OR NEGLECT.

THESE TWO CASES WERE IN THE JUDICIAL STREAM IN INDIANA. THE FIRST CASE, HEARD BY JUDGE BAKER, WAS APPEALED TO THE INDIANA SUPREME COURT. THAT COURT SAID THAT JUDGE BAKER HAD ACTED APPROPRIATELY AND HAD NOT EXCEEDED HIS AUTHORITY. THE INDIANA SUPREME COURT, HOWEVER, DID NOT REVIEW THE SUBSTANCE OF JUDGE BAKER'S DECISION. THE PLAINTIFFS -- PHYSICIANS OF BLOOMINGTON HOSPITAL -- APPEALED NEXT TO THE UNITED STATES SUPREME COURT.

ON APRIL 15, SEVEN DAYS AFTER HE HAD BEEN BORN, "BABY DOE" DIED. IN A MATTER OF HOURS, MR. JUSTICE JOHN PAUL STEVENS WAS TO HAVE HEARD A REQUEST THAT THE INDIANA SUPREME COURT DECISION BE OVER-RULED. BUT WITH THE BABY'S DEATH, THE REQUEST WAS MOOTED. THE SECOND CASE HAD THE SAME FATE. IT ALSO WAS MOOTED AT THE INDIANA APPELLATE LEVEL.

HENCE, EXCEPT FOR THAT FIRST TIME AROUND IN JUDGE BAKER'S COURT, THE SUBSTANCE OF THE "BABY DOE" ISSUE HAS NEVER BEEN THOROUGHLY ADJUDICATED...IN INDIANA, IN WASHINGTON, IN NEW YORK...ANYWHERE.

IT'S IMPORTANT TO REVIEW THIS INFORMATION BECAUSE ALL THE ELEMENTS OF THE "BABY DOE" CONTROVERSY OVER THE PAST 2 AND A HALF YEARS WERE RIGHT THERE IN THE ORIGINAL CASE. AND FOR THE NEXT SEVERAL MINUTES I WANT TO GO OVER THEM FOR YOU, FROM MY PERSPECTIVE...AS A SURGEON...AS A PHYSICIAN...AND AS SURGEON GENERAL.

FIRST, LET'S LOOK AT THE MEDICAL SIDE OF THIS ISSUE.

THE INITIAL DIAGNOSIS OF "BABY DOE" BY SOME OF THE BLOOMINGTON MEDICAL STAFF RAISED SOME EYEBROWS. WHILE IT IS TRUE THAT SURGERY TO REPAIR ESOPHAGEAL ATRESIA IN A NEWBORN CAN BE DIFFICULT AND TRICKY, IT IS ALSO TRUE THAT THE SUCCESS RATE IS VERY HIGH. IN THE LAST 7 YEARS OF MY EXPERIENCE, EVEN PREMATURE BABIES WITHOUT ADDITIONAL ANOMALIES HAD A SURVIVAL RATE OF 88 PERCENT. SO THE SURGICAL COMMUNITY HAD SOME LEGITIMATE QUESTIONS TO ASK CONCERNING THE ADVICE THE SURGEON GAVE TO THE PARENTS OF "BABY DOE."

AND WE HAD TO QUESTION THE PHYSICIAN'S COUNSEL, ALSO. WE ARE GIVEN TO UNDERSTAND THAT THAT PERSON HAD INDICATED TO THE PARENTS THAT THE QUALITY OF "BABY DOE'S" FUTURE LIFE WOULD NOT BE VERY GOOD. THIS ALSO RAISED SOME EYEBROWS. THERE IS SIMPLY NO WAY THAT A PHYSICIAN CAN PREDICT WITH ANY ACCURACY AT ALL JUST WHAT THE "QUALITY OF LIFE" WILL BE FOR A CHILD BORN WITH DOWN SYNDROME.

THE SCALE OF RETARDATION CAN PASS FROM MILD TO SEVERE. AND AT EVERY POINT ON THAT SCALE, THE "QUALITY OF LIFE" IS AFFECTED BY THE CHILD'S FAMILY, THE RESPONSE OF THE COMMUNITY, AND THE KIND AND DEGREE OF MEDICAL AND HEALTH SERVICES THAT ARE AVAILABLE. I WOULD ONLY WISH, FOR EXAMPLE, THAT THE PHYSICIAN WHO ADVISED "BABY DOE'S" PARENTS MIGHT HAVE THE PRIVILEGE OF ATTENDING JOSHUA ROSENBLUM'S BAR MITZVAH THIS MORNING.

SO THERE WERE SERIOUS QUESTIONS CONCERNING THE MEDICAL COUNSEL RECEIVED BY THE PARENTS OF "BABY DOE." SOME PEOPLE IN BLOOMINGTON, AS WELL AS SOME OF US WASHINGTON, THOUGHT THAT MAYBE THE PARENTS HADN'T BEEN GIVEN TOTALLY ACCURATE, BIAS-FREE, PROFESSIONALLY CONSERVATIVE INFORMATION ABOUT THE CONDITION OF THEIR NEW BABY BOY.

BUT SECOND, I THINK THE POINT MUST BE MADE -- AND EMPHASIZED -- THAT THOSE OF US IN WASHINGTON WHO WERE ASKED TO BECOME INVOLVED WERE RELUCTANT TO DO SO.

SINCE THE MEDICAL RECORDS WERE SEALED BY THE COURTS, WE DID NOT HAVE AVAILABLE TO US ALL THE PERTINENT INFORMATION. I WAS ASKED TO DO SOME LONG-DISTANCE HYPOTHESIZING ABOUT "BABY DOE'S" CHANCES, BUT I REFUSED. I BELIEVED THEN -- AND I GREW TO BELIEVE IT MORE INTENSELY LATER -- THAT THESE KINDS OF PROBLEMS CAN BE ANSWERED BEST BY CLEAR-THINKING, RESPONSIBLE PEOPLE WHO ARE RIGHT THERE ON THE SCENE.

AS IT TURNED OUT, WHEN "BABY DOE" DIED ON APRIL 15, 1982, A WEEK AFTER BIRTH, THE DEATH CERTIFICATE INDICATED "MULTIPLE CONGENITAL DEFECTS." BUT WHAT DID THIS MEAN?:

- * WAS THERE IRREPARABLE HEART DAMAGE? NEARLY HALF OF ALL DOWN'S SYNDROME INFANTS ARE BORN WITH CONGENITAL HEART DISEASE AND THE MORTALITY RATES FOR SUCH INFANTS ARE VERY HIGH.

- * WAS THERE IRREVERSIBLE BRAIN DAMAGE?

* OR WERE THE "MULTIPLE DEFECTS" ONLY THE 2 I HAVE ALREADY DISCUSSED...THAT IS, DOWN SYNDROME AND ESOPHAGEAL ATRESIA?

IN ANY CASE, THE PUBLIC DIDN'T HAVE ANY OF THIS INFORMATION BETWEEN APRIL 8 AND APRIL 15, 1982. WE DIDN'T HAVE IT THEN...AND WE STILL DON'T HAVE IT NOW.

"BABY DOE" REMINDED US THAT FOR HIM...AS FOR MANY OF OUR PATIENTS...WE HAVE NO CURES. BUT WE CAN OFFER SOMETHING ELSE JUST AS VALUABLE. WE CAN OFFER SUCH PATIENTS A LOT OF GENUINE CARE. THEY MAY STILL NEED US AS PEOPLE, EVEN THOUGH WE CAN'T DO VERY MUCH FOR THEM AS PHYSICIANS.

THAT'S AN IMPORTANT MESSAGE. BUT IT'S A DEMANDING MESSAGE. IT DEMANDS THAT WE LAY ASIDE OUR MEDICAL TEXTS AND, INSTEAD, SIT DOWN AND WORK THROUGH THOSE QUESTIONS AND ANSWERS THAT ARE SPUN OUT OF THE DEPTHS OF OUR CONSCIENCE...NOT OUT OF MEDICAL TEXTS AND JOURNALS.

MY CONSIDERED JUDGMENT -- WORKED OUT OVER SOME YEARS -- TELLS ME THAT WE OUGHT TO DO THOSE THINGS THAT GIVE A PERSON ALL THE LIFE TO WHICH HE OR SHE IS ENTITLED, BUT NOT DO ANYTHING THAT WOULD VAINLY EXTEND THAT PERSON'S ACT OF DYING.

IN MY PEDIATRIC SURGICAL PRACTICE I HAD COME UPON THIS KIND OF SITUATION BEFORE. NOT OFTEN..BUT ENOUGH TIMES SO THAT THE EXPERIENCE WAS ENGRAVED IN MY MIND FOREVER:

A TRAGICALLY DISABLED CHILD...PARENTS WHO ARE CONFUSED, ANGRY, GRIEVING...A DIVIDED MEDICAL STAFF. WHAT THEN?

WITH "BABY DOE," THERE WERE SO MANY FACETS TO DEAL WITH, EVEN IF THERE WAS NOTHING MORE TO THE DIAGNOSIS THAN WHAT WE LEARNED FROM THE NEWSPAPERS. ORAL INTAKE WAS IMPOSSIBLE BECAUSE OF THE ESOPHAGEAL LESION. PARENTERAL ALIMENTATION WOULD NOT SOLVE THE PROBLEM -- EVEN TEMPORARILY -- BECAUSE PULMONARY ASPIRATION OF PHARYNGEAL SECRETIONS AND OF GASTRIC JUICE THROUGH THE TRACHEO-ESOPHAGEAL FISTULA WOULD BE LETHAL.

THIS IS QUITE DIFFERENT FROM THE DECISION SOME ARRIVE AT, OF NOT TREATING AN OPEN MYELOMENINGOCELE, BUT FEEDING THE INFANT MEANWHILE.

THE THIRD ELEMENT IN THIS CASE -- AND THE LAST ONE I WILL HIGHLIGHT -- WAS THE FACT THAT "BABY DOE" DOES NOT FIT NEATLY INTO ANY OF OUR LEGAL PIGEONHOLES.

FOR EXAMPLE, THE COURT FIRST CASE FILED IN BLOOMINGTON BY SOME OF THE MEDICAL STAFF WAS BASED ON THE INDIANA STATE LAW REGARDING CHILD ABUSE AND NEGLECT, AS I'VE MENTIONED. BUT "BABY DOE" WAS NOT THE USUAL VICTIM OF CHILD ABUSE AND NEGLECT...THAT IS, HE WAS NOT A NORMAL, HEALTHY CHILD WHO BECAME THE VICTIM OF PARENTAL VIOLENCE.

THE KEY TO THIS CASE, THEN, WAS THE CHILD'S HANDICAPPING CONDITION. THIS IS WHAT MADE IT NEWSWORTHY...THIS IS WHAT MADE THE CIRCUMSTANCES PARTICULARLY TROUBLING...AND WHAT STIMULATED A NUMBER OF PEOPLE IN INDIANA, ELSEWHERE IN THE COUNTRY, AND IN WASHINGTON TO THINK ABOUT "BABY DOE" AS A VICTIM OF DISCRIMINATION INSTEAD OF -- OR IN ADDITION TO -- BEING A VICTIM OF ABUSE AND NEGLECT.

NOW WE HAD TO ASK IF THE CARE GIVEN TO "BABY DOE" WAS THE KIND OF CARE ANY BABY WITH ESOPHAGEAL ATRESIA WOULD RECEIVE? MANY PEOPLE THOUGHT NOT. THE ASSOCIATED DOWN'S SYNDROME WAS, THEREFORE, EXTREMELY SIGNIFICANT. HAD "BABY DOE" HAD ONLY DOWN'S SYNDROME, HE WOULD HAVE BEEN NOURISHED AND CARED FOR. HAD HE HAD ONLY ESOPHAGEAL ATRESIA, HE WOULD HAVE BEEN OPERATED ON AND CURED.

EVENTUALLY THE ARGUMENT CENTERED AROUND SECTION 504 OF THE REHABILITATION ACT OF 1973, OR PUBLIC LAW 93-112. THAT SECTION SAYS THAT "NO OTHERWISE QUALIFIED HANDICAPPED INDIVIDUAL...SHALL, SOLELY BY REASON OF HIS HANDICAP, BE EXCLUDED FROM THE PARTICIPATION IN, BE DENIED THE BENEFITS OF, OR BE SUBJECTED TO DISCRIMINATION UNDER ANY PROGRAM OR ACTIVITY RECEIVING FEDERAL FINANCIAL ASSISTANCE."

THIS IS ALMOST IDENTICAL TO THE LANGUAGE OF TITLE VI OF THE CIVIL RIGHTS ACT OF 1964 AND OF TITLE IX OF THE EDUCATION AMENDMENTS OF 1972. AS YOU KNOW, THOSE TWO LAWS FORBID ANYONE USING FEDERAL FUNDS FROM DENYING BENEFITS OR SERVICES TO A BLACK PERSON BECAUSE HE OR SHE IS BLACK...OR AN HISPANIC PERSON...OR AN ASIAN...OR AN ELDERLY PERSON...OR A WOMAN.

IRONICALLY, WHILE THERE WERE FEDERAL REGULATIONS ON THE BOOKS WITH WHICH TO ENFORCE TITLES VI AND IX, THERE WERE STILL NO REGULATIONS FOR ENFORCING SECTION 504. THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE -- AS WE WERE THEN KNOWN -- HAD PROPOSED SOME DRAFT RULES IN 1976 AND 1977, BUT JUST NEVER GOT AROUND TO PUTTING OUT THE FINAL REGULATIONS.

I ALSO WANT TO MENTION ONE OTHER MATTER OF LAW THAT CAME UP EARLY IN THE HISTORY OF "BABY DOE." AND IT REMAINS AS AN ISSUE FOR MANY PEOPLE. BRIEFLY STATED, IT IS THIS:

DOES THE STATE HAVE ANY BUSINESS AT ALL TO STEP INTO A MATTER AFFECTING A NEWBORN CHILD AND GO OVER THE HEADS, SO TO SPEAK, OF THE PARENTS?

AS YOU KNOW, WHEN THE "BABY DOE" CASE FIRST HIT THE NEWSPAPERS, A NUMBER OF PEOPLE SAID THE GOVERNMENT "HAD NO RIGHT" TO INTERFERE IN A MATTER THAT WAS THE RESPONSIBILITY ONLY OF THE PARENTS AND OF THE ATTENDING PHYSICIANS. BUT THE ISSUE IS NOT THAT SIMPLE. WE HAVE TRUANCY LAWS AND CHILD ABUSE LAWS AND IMMUNIZATION LAWS AND SO ON, WHERE THE STATE DOES INTERFERE AND IS NOT CHALLENGED.

IT'S POSSIBLE THAT THOSE LAWS SEEM TO BE ACCEPTED MAINLY BECAUSE, FOR THE MOST PART, THEY CONCERN CHILDREN WHO ARE NO LONGER INFANTS. I'VE OFTEN THOUGHT THAT, IF THE "BABY DOES" OF THIS WORLD WERE 35 YEARS OLD, THEY WOULD HAVE A NATIONAL ADVOCACY ORGANIZATION AND A STRONG CONGRESSIONAL LOBBY. UNFORTUNATELY THEY ARE TOO SMALL, TOO WEAK, AND TOO POOR.

THERE IS NO CONSTITUTIONAL DEFINITION OF HOW OLD SOMEONE HAS TO BE IN ORDER TO RECEIVE THE PROTECTION OF THE STATE. THERE IS NO MINIMUM-AGE REQUIREMENT FOR NATIVE-BORN CITIZENSHIP.

FOR EXAMPLE, AN AMERICAN-BORN CHILD DOES NOT HAVE TO REMAIN IN THE UNITED STATES FOR A MONTH...OR TWO WEEKS...OR EVEN FOR ONE HOUR IN ORDER TO QUALIFY FOR A SOCIAL SECURITY NUMBER. THE CHILD MERELY HAS TO BE "BORN" AS AN AMERICAN. ODDLY ENOUGH THE PEOPLE WHO PROBABLY KNOW THIS BEST ARE THOSE PREGNANT MEXICAN WOMEN WHO SLIP ACROSS THE RIO GRANDE TO HAVE THEIR BABIES BORN ON UNITED STATES SOIL. THEY KNOW THAT SUCH CHILDREN ARE U.S. CITIZENS AND CAN THEREFORE SEEK THE PROTECTION OF OUR LAWS FROM BIRTH ON.

I DON'T FIND THAT DIFFICULT TO UNDERSTAND. I NEVER DID. AND, FOLLOWING THAT SAME LOGIC, I BELIEVE THAT A NEWBORN INFANT WHOSE LIFE IS PUT AT RISK BY A PARENT, A GUARDIAN, A PHYSICIAN, OR BY WHOMEVER -- I BELIEVE THAT CHILD IS A CITIZEN AND DESERVES TO BE ACCORDED THE FULL PROTECTION OF THE STATE.

"BABY DOE'S" LIFE BEGAN WITH MANY TRAGIC COMPLICATIONS. BUT I AM CONVINCED THAT...

NONE OF THOSE HANDICAPS PUT HIM OUTSIDE THE PROTECTION OF THE LAW...

NONE OF THEM RELIEVED THE STATE OF ITS OBLIGATION TO PROTECT HIM...

NONE OF THEM PERMITTED ANYONE TO FURTHER JEOPARDIZE HIS HEALTH OR HIS LIFE...

NONE OF THEM.

I DON'T WANT TO BORE YOU WITH HISTORIC DETAILS BUT YOU SHOULD KNOW AT LEAST THIS:

- * EARLY IN 1983, DURING THE INTERVAL BETWEEN SECRETARIES OF H.H.S. SCHWEIKER AND HECKLER, AN INTERIM FINAL RULE WAS PROMULGATED. I HAD NOTHING TO DO WITH THIS.
- * THIS RULE WAS STRUCK DOWN AS THE RESULT OF A SUIT BROUGHT BY A COALITION OF PROFESSIONAL AND VOLUNTARY ORGANIZATIONS ON PROCEDURAL GROUNDS, NOT ON THE SUBSTANCE OF THE RULE.
- * THEN A "NOTICE OF PROPOSED RULE-MAKING," WITH A COMMENT PERIOD, WAS PUBLISHED IN JULY 1983. AGAIN, I HAD NO VOICE IN THIS RULE EITHER.
- * THE DEPARTMENT RECEIVED 17,000 COMMENTS FOLLOWING THE JULY PUBLICATION OF THE NOTICE.

- * IN NOVEMBER 1983 I ASKED SECRETARY HECKLER FOR THE PRIVILEGE OF TAKING A ROLE IN THE WRITING OF THE FINAL RULE, INASMUCH AS I WAS RECEIVING NEARLY ALL THE PUBLIC CRITICISMS ANYWAY. AND SHE AGREED.
- * MEANWHILE, THE AMERICAN ACADEMY OF PEDIATRICS IN CONCERT WITH OTHER MAJOR ORGANIZATIONS SERVING DISABLED PERSONS PREPARED ONE OF THE MOST IMPORTANT MEDICAL DOCUMENTS IN MY LIFETIME: IT WAS TITLED "PRINCIPLES OF TREATMENT FOR HANDICAPPED NEWBORNS" AND WAS INTRODUCED AT A PRESS CONFERENCE IN NOVEMBER.
- * USING THIS DOCUMENT AND CONSULTATION WITH THE AUTHORS, WE DRAFTED AND PUBLISHED A FINAL RULE ON JANUARY 13, 1984. CONSIDERING ALL THE CONSTRAINTS AND ALL THE POLITICAL AS WELL AS MEDICAL POT-HOLES THAT WERE IN OUR PATH, I BELIEVE WE CAME UP WITH A GOOD REGULATION THAT WOULD HAVE WORKED WITH A MINIMUM OF DIFFICULTY - IF THAT.

- * BUT THAT REGULATION BECAME MOOT AFTER A SUIT BY THE AMERICAN MEDICAL ASSOCIATION, WHO CLAIMED THAT THE LEGISLATIVE HISTORY OF THE REHABILITATION ACT OF 1973 DID NOT INDICATE THAT CONGRESS INTENDED TO COVER HANDICAPPED NEWBORNS UNDER THAT LAW.

THE ETHICAL ISSUES REMAIN, AND THEY'VE SHOWN LIKE SPOTLIGHTS, REVEALING SHARP DIVISIONS WITHIN THE MEDICAL COMMUNITY. PHYSICIANS -- LIKE THE REST OF AMERICANS -- ARE DEEPLY TROUBLED BY "BABY DOE" AND ARE UNSURE OF WHAT THEIR POSITION SHOULD BE.

ALTHOUGH OUR DEPARTMENT HAS BEEN SUED BY DIFFERENT PHYSICIANS' ORGANIZATIONS, I THINK IT IS CLEAR THAT THERE IS NO SINGLE POSITION THAT CAN BE LABELLED AS REPRESENTING THE THINKING OF "ORGANIZED MEDICINE." INDEED, IT IS STILL DIFFICULT TO FIND CONSENSUS ON ALMOST ANY ASPECT OF THIS ISSUE. BUT ON SOME THINGS I THINK MOST OF US HERE TODAY MIGHT AGREE. FOR INSTANCE...

"BABY DOE," A TINY BABY BOY WITH "MULTIPLE CONGENITAL DEFECTS," HAS FIGURATIVELY TAKEN AMERICA BY THE SHOULDERS AND HAS GIVEN US A GOOD SHAKE. THAT HAS CERTAINLY HAPPENED.

"BABY DOE" HAS ALSO ASKED US TO CONFESS HOW WE REALLY FEEL ABOUT OUR FELLOW HUMAN BEINGS. LIKE IT OR NOT, THAT HAS HAPPENED, ALSO.

AND, AFTER THE RHETORIC DIES DOWN, "BABY DOE" RE-APPEARS AND PRODS US INTO REVEALING WHETHER WE ARE -- OR ARE NOT -- THE FRIENDS OF THE HELPLESS, THE WEAK, THE HURT, THE INJURED, AND THE TROUBLED.

IN FACT, "BABY DOE" HAS LITTLE PATIENCE FOR MOST OF THE RHETORIC AND THEORY THAT HAS BEEN PASSED AROUND....HE WILL NOT STAND FOR ARGUMENTS THAT DEFEND SOME PERCEIVED THREATS TO SELF-INTEREST...AND "BABY DOE" WILL NOT PATIENTLY WAIT IN THE BACKGROUND WHILE THE INSTITUTIONS OF MEDICINE AND LAW AND RELIGION AND GOVERNMENT FIGHT FOR SOME TEMPORARY PRIMACY.

HE DID NOT PRESENT A PROFOUND MORAL AND ETHICAL CHALLENGE ONLY TO HIS PARENTS AND TO THE MEDICAL STAFF OF BLOOMINGTON HOSPITAL. HE CHALLENGED US ALL.

THE CONGRESS, IN THE LATEST CHAPTER OF THIS MAJOR PUBLIC ISSUE, RECENTLY ENACTED CHILD ABUSE LEGISLATION, COMPLETE WITH "BABY DOE" AMENDMENTS. IT HAS SINCE BEEN SIGNED BY THE PRESIDENT AND IS PUBLIC LAW 00-000. INSTEAD OF FEDERAL MONITORING UNDER CIVIL RIGHTS LAW, THERE WILL BE MONITORING AND ENFORCEMENT BY STATE CHILD ABUSE AGENCIES UNDER PERTINENT CHILD ABUSE AND NEGLECT LEGISLATION, WHICH, AS IT SO HAPPENS, WAS THE ROUTE FOLLOWED BY THE PHYSICIANS AND BY THE LOCAL GOVERNMENT IN THE ORIGINAL "BABY DOE" CASE IN BLOOMINGTON.

I DO BELIEVE OUR APPROACH IN THE EXECUTIVE BRANCH WOULD HAVE BEEN ALL RIGHT -- PROVIDED THE MEDICAL COMMUNITY AND THE PUBLIC HAD DECIDED TO CHOOSE THE LIFE OPTION FOR HANDICAPPED CHILDREN.

AND I'M SURE THE APPROACH OF THE CONGRESS CAN WORK, TOO -- IF PHYSICIANS AND SURGEONS AND MOTHERS AND FATHERS AGREE NOT TO MAKE LIFE-OR-DEATH DECISIONS ON THE BASIS OF WHAT IS GOOD OR CONVENIENT OR FINANCIALLY FEASIBLE FOR THEM BUT, RATHER, WHAT IS THE ETHICAL IMPERATIVE ON BEHALF OF A DISABLED INFANT IN THEIR CARE.

YOU SEE, WHEN WE SAY, "'BABY DOE' HAS A LIFE THAT'S NOT WORTH LIVING," ARE WE NOT REALLY SAYING, "IT'S NOT WORTH IT TO US TO CARE FOR HIM"?

OUR LIVES -- AS HEALTH PROFESSIONALS -- AND THE LIVES OF THE PARENTS AND THE DISABLED ARE REMARKABLY SHAPED BY THE CARE WE GIVE THE HANDICAPPED. I THINK MY 40 YEARS OF HANDS-ON EXPERIENCE HAS CONVINCED ME THAT ALL APSECTS OF MEDICAL ETHICS ARE DWARFED BY THE QUESTION:

"HOW OUGHT WE TO CARE FOR THOSE WHO CANNOT -- IN ONE WAY OR IN EVERY WAY -- CARE FOR THEMSELVES?"

WHEN WE'VE SETTLED THAT QUESTION, THEN WE CAN TURN TO THE OTHERS...FINANCES, RESOURCES, COMMITTEES, AND SO ON.

NO ONE SAID IT WOULD BE EASY. I'M NOT EVEN SUGGESTING THAT WE HAVE AN OBJECTIVE AND GENERALLY ACCEPTED WAY TO PROCEED. WHAT I AM SAYING IS THAT THE QUALITY OF LIFE WE TALK SO MUCH ABOUT IS MORE THAN JUST A PLEASANT PHRASE, A BENIGN THEORY. IT IS A SUMMATION...AN AGGREGATE OF WHO WE ARE AND WHAT WE WANT TO BE. AND SO, OUR DAY-TO-DAY DECISIONS TO ACT...TO SERVE...AND TO CARE ABOUT CHILDREN WITH DOWN'S SYNDROME OR WITH ANY OF A THOUSAND OTHER DISABLING CONDITIONS, WHEN ADDED TOGETHER, WILL PRODUCE A SUM THAT REVEALS THE QUALITY OF OUR OWN LIVES.

I WOULD SAY THAT SUCH AN EXCURSION INTO "HIGHER MATH" IS NOT LOST ON THE MEMBERS OF THIS AUDIENCE.

LET ME CLOSE BY SAYING THAT IT HAS BEEN A PRIVILEGE AND A DISTINCT PERSONAL PLEASURE TO HAVE JOINED YOU THIS MORNING. BEST WISHES FOR A SUCCESSFUL MEETING...AND PLEASE, PLEASE KEEP UP THE GOOD WORK.

THANK YOU.

#